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ORIGINAL RESEARCH MANUSCRIPT

Long-term conditions, self-management and systems of support: An exploration of health beliefs and practices within the Sikh community, Birmingham, UK

Abbreviated title: Self-management within the Sikh community, UK

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Abstract

Objective

The global prevalence of non-communicable diseases (NCDs), such as diabetes mellitus and coronary heart disease, continues to rise. Internationally, people of South Asian origin (i.e. by birth or heritage) are much more likely to develop and live with NCDs compared to the general population. The South Asian diaspora population is highly heterogeneous, varying by socioeconomic status, migration history, religion and ethnicity. This article reports the

findings of a study to explore the types of support accessed by Punjabi Sikhs living in Birmingham and the Black Country, UK, who were living with NCDs.

Design

The study sought to develop a greater understanding of past experiences of accessing support and the importance of relationships in the mobilisation of resources for self-management. It was nested within a larger programme of research which explored attitudes to prevention of NCDs in local communities in the region. Seventeen Punjabi Sikh men and women were recruited through purposive sampling. Narrative interviews were conducted and analysed by the research team. Sociological theories on systems of support and social relations were consulted to inform the interpretation of data.

Results

The study findings suggest that participants interpreted NCD self-management in relation to four primary systems of support: health services for disease management; multiple sources of care, including traditional Indian medicines and the internet, for symptom management; community groups for lifestyle management; and the family for emotional and physical care. Within these systems of support, participants identified barriers and facilitators to the maintenance of a healthy lifestyle. We focus on intra-group diversity; exploring the intersection of views and experiences by age, gender, generation and caste.

Conclusion

The findings have implications for the design and delivery of primary care and community services which support the prevention and management of NCD in an increasing diverse population.

Key words:

Ethnicity, self-management, CHD/CVD, Diabetes, South Asian, Sikh, non-communicable disease.

Long-term conditions, self-management and systems of support: An exploration of health beliefs and practices within the Sikh community, Birmingham, UK

Introduction

Due to the growing global prevalence of non-communicable diseases (NCDs), the ability (or perceived inability) to self-manage long-term conditions has been attracting considerable attention from researchers and policy makers. However, the focus has largely been on particular medical conditions with far fewer attempts to understand how that experience may vary according to the interacting effects of socioeconomic circumstances, ethnicity, generation and locality (Schulz & Mullings, 2006). People of South Asian origin, and particularly men, have a higher risk of developing conditions such as diabetes mellitus (DM) and coronary heart disease (CHD) (Gill et al., 2007). Yet, there is still considerable debate concerning the configuration of genetic, cultural and socioeconomic factors which lead to ethnic health inequalities in CVD and more broadly. Empirical studies which focus on the importance of social group and culture, whilst also acknowledging the context and flexible nature of ethnicity, are still needed (Nazroo, 1998). As part of a larger mixed methods study examining secondary prevention of vascular disease in Birmingham and the Black Country, United Kingdom (UK), we explored the health and self-management practices of Punjabi Sikh participants in relation to prevention of vascular disease. Local populations in Sandwell, Birmingham and Solihull have been shown to have significantly higher mortality rates from cardiovascular disease compared to other areas in the UK (South East Public Health Observatory, 2012).

Against this background of increased risk, we document the ‘systems of support’ (Rogers et al., 2011) that migrant and British-born men and women from the Punjabi Sikh community

draw on to manage their health. We argue that adding a further dimension to this model, by sub-categorizing self-management into four groups (management of disease, symptoms, lifestyle and embodied wellbeing), has useful descriptive and explanatory value. In doing so, we contribute to the literature that highlights the importance of understanding the emergence of health practices not simply as a product of ‘cultural difference’ but as socially embedded, embodied and emergent practices.

Migration, settlement and health inequalities

At present, there are four main South Asian communities living in the UK which were part of the mass migration movement of the 1950s and 1960s: Muslims from Pakistan and Bangladesh (predominantly from the Mirpur and Sylhet region respectively), Muslims and Sikhs from northern India, and Hindus from Gujarat (and across India). Social policy in the UK has been influenced by multiculturalism that celebrates cultural difference and diversity (Solomos, 1998). Recent approaches have moved beyond static versions of multiculturalism (Nye, 2007) to acknowledge a ‘dynamic interplay of variables’ (Vertovec, 2007) in contemporary health inequalities.. There are new challenges for health services which seek the best way to deliver services closer to home (rather than in acute care), which also seek to reduce ethnic inequalities in the incidence and experience of long-term conditions. Culturally-adapted health services have developed and staff from minority-ethnic groups have been employed to deliver care in community languages within community settings. Recognition of diversity can be seen as a positive development in health policy because it challenges the assumption that research and practice designed for the majority White British population can be generalized or transferred to minority ethnic groups. Investigating the lifestyle, health service use and self-management techniques of participants from a Punjabi Sikh population known to be at higher risk of long-term conditions, offers a way to

understanding how a number of factors such as health beliefs, locality, ethnicity and the availability of health care resources coincide.

Bhopal (2002) refers to the ‘fallacy of homogeneity’ where labels such as ‘South Asian’ hide the true extent of diversity between ethnic sub-groups. Furthermore, focusing on ethno-religious identities is supported by literature citing the level of heterogeneity of lifestyle practice across South Asian sub-groups (Nazroo, 1997).

From the outside, concentrations of minority-ethnic communities can be perceived as inward-looking but seemingly bounded populations are increasingly transnational, and the intensity of ties, interactions, exchange and mobility between the boundaries of the nation state is rapidly increasing (Vertovec, 1999). Consequently, the prevalence of community networks and resources, existing in parallel to mainstream health services, means understanding the complexity of medical pluralism and its application to health service design needs to be readdressed, for example, whether formal health services can be delivered with greater integration with current informal self-care practices.

Within the West Midlands, the Sikh community is well established, demonstrated by places of worship, faith-based schools and local enterprises. 4.3% of the population of the West Midlands (116, 715) describe themselves as Sikh (ONS, 2012). Of those, 56.6% were born in the UK and 87% are from an Asian ethnic background (ONS, 2012). 76.0% of Sikhs are aged 49 years or less (of which 34.4% aged 24 years or less), compared to 65.4% for the general UK population (ONS, 2012). Since migration, Punjabi Sikhs have experienced relative social mobility with 69% currently economically active (second only to Hindus with 70%). Yet, Sikhs in the UK reflect a wide spectrum of social class and members live in concentrations

across deprived areas of the Birmingham, showing limited access and uptake of preventative health services.

Living with non-communicable diseases and self-management

Studies of the social, cultural, emotional and spiritual aspects of living with NCDs have grown into a major strand of research in the applied health sciences and social sciences.

Researchers have often attempted to incorporate ethnic diversity into their sample (Lawton et al., 2007), with some noteworthy attempts considering differences across ethnic groups. For instance, Patel et al. (2011), with a substantial sub-sample of Gujarati Hindus, found the disclosure of type 1 diabetes, in the context of marriage prospects for younger members of the community, was a great concern.

These studies have had implications for practice: a review by Zeh et al. (2014) identified a number of cultural barriers for minority ethnic groups accessing diabetes care, with commitment to religious beliefs, linguistic differences between patients and health workers, and low concordance with professional medical advice the most pertinent themes concerning Muslims, Hindus and Sikhs. Stone et al. (2013) found that cultural awareness training for health care providers led to increased confidence, knowledge and self-awareness, which were perceived to enhance quality of interaction between provider and patient. Hipwell (2008), encouraged healthcare providers to acknowledge both their own culture and spirituality, and that of their clients.

However, the focus of many explorations has been around specific medical diagnoses rather than sociologically-informed groupings. If we are to take seriously the idea that illness is managed not just by doctors or the ‘patient’ but through individuals embedded in social

networks of family, community and health professionals, then simply understanding disease experiences and associated health beliefs from those who have specific conditions is a limiting strategy. Health policy is shaped by the biomedical model with a disproportionate focus on self-management as an individual behaviour related to medical outcomes or symptom control to the neglect of broader, contextual experiences of maintaining a sense of normality (Charmaz, 1983), social isolation (Williams, 2000) or general wellbeing (Lawton, 2003). While there is a growing literature about the changing nature of the relationship there is much less attention given to how self-management is shaped by the networks of relationships outside the formal health system.

Systems of support and the mobilisation of self-management resources

‘Systems of support’ is a concept that refers to the mobilisation of resources by individuals in pursuit of health (Rogers et al., 2011). The concept allows for greater consideration of the wider social environment in which self-management practices occur (Vassilev et al., 2011). Rogers et al. identified four systems of support: health professionals, such as GPs, nurses, or physiotherapists; non-health professionals, such as health trainers, traditional healers, religious leaders or teachers; voluntary and community groups, such as internet-based discussion groups, ethnic groups, sports groups and other social groups; and personal communities, including spouse/partner, family members, friends, neighbours, colleagues and even pets. Studies of social networks have usefully utilised the concepts of ‘nodes’ (the individuals involved in a network) and ‘ties’ (the nature of the relationships between them). The nature of ties can be described and categorized, for instance in terms of direction (one way or reciprocal), emotion or cognition (affective or cognitive ties), or role (doctor, student, kin) (Marin and Wellman, 2011). In this article, we aim (1) to analyse the extent to which the

experiences and perceptions of self-management for long-term conditions of people from the Punjabi Sikh community in Birmingham can map onto the systems of support model, (2) to describe the nature of the support sought from different systems, (3) to describe the characteristics of the ties present within each system, and (4) to examine the implications of these findings for public health work on prevention of CVD, DM and other long-term conditions that disproportionately affect South Asian diasporas.

Methods

Study Design

Our overarching research question for this part of the study was: How are health practices related to the prevention of NCDs and the promotion of health, and sources of support for these practices, described and explained by Punjabi Sikh participants in Birmingham? We selected a community-based, qualitative interview approach because: (i) it enabled us to collect accounts of lay knowledge and experience and to privilege subjective meaning; (ii) talk-based methods (using Punjabi where appropriate) were most suitable for a migrant community where there were low levels of literacy in the first generation. In order to access accounts from individuals within the community that could shed light on these questions of how health practices are shaped through social interactions and what the patterns and character of those interactions might be, we sought to elicit contextually-embedded accounts, in the form of ‘stories’ from individuals within the community.

Access and Recruitment

Posters about the study in English and Punjabi were displayed in GP surgeries, temples and community organisations in areas of Birmingham with a high Punjabi Sikh population and we attempted to organise informal information sessions in temples where participants could

learn about the study. Due to difficulties of arranging meetings with volunteers working within organisations and the failure to recruit any via posters, which led to time delays, we pursued a strategy using gatekeepers. Gatekeepers were family members of one of our research team (MS) who had a well-established network of contacts. Gatekeepers made contact with potential participants known to have long-term conditions. Those who agreed were provided with additional information about the study. If they agreed to participate, arrangements were made for the interview and written informed consent was taken immediately before the interview commenced.

Sampling

Participants were chosen using a purposive sampling method, (Denzin and Lincoln, 1994) with the aim of selecting families, including two or three generations where at least one family member currently had diabetes and/or cardiovascular disease. We selected a snowballing sampling method, where initial contacts would facilitate the identification of other, potential respondents. The sampling frame was devised to seek maximum diversity in terms of age, gender and caste of participants (NB: extent of religious beliefs varies within and across caste groups). Our objective was to distinguish between views expressed by migrant and British-born members of the community, and between those living with NCDs and those who were 'at risk'.

Data collection

Conventional data collection methods, such as including only people who speak English, can serve to deliberately exclude people from participating in research (Redwood et al., 2012). MS conducted all the interviews in English or Punjabi and adopted a 'sharing stories' style during interviews which may suit South Asian populations better (Greenhalgh, 2001). In the

interviews, MS (with the *aide memoire* of a topic guide) and the participant constructed ‘stories’ covering a range of areas. Participants were asked questions regarding healthy living, self-care and accessing health services. This led to the emergence of cultural practices as symbolic demonstrations of pluralistic identities, accessing a limited amount of self-care support outside of primary care, and cultural adaptation as important areas to follow up in greater depth in later interviews. Example questions included discussing lifestyle practices in the context of different social groups, attitudes to alternative remedies/treatments, and the role of religion in participant’s lives. Interviews lasted between 40 and 90 minutes.

Interviews were conducted in participant’s homes or at the University of Birmingham. Data were collected between May and September 2011. All interviews with first generation participants were conducted in Punjabi. In carrying out the interviews, MS placed emphasis on ensuring participants understood the overall purpose of the interview and the questions, while paying on-going reflexive and critical attention to interpreting the social context behind accounts. Interviews were audio-taped, translated into English and transcribed by MS. Participants were informed of their right to withdraw from the study at any time and assured that their personal details would be kept confidential. Ethical approval was obtained from South Birmingham Research Ethics Committee.

Data analysis

We used two cycles of analysis. In the first cycle, we adopted a qualitative content analysis approach to compare the accounts on a similar range of topics. Two of the members of the team [MS, NG] applied open codes to two transcripts then developed a descriptive coding framework used for the remainder with modifications (Saldana, 2009). Transcripts were coded with NVivo 8. During the first cycle, the team met regularly (monthly [KJ, MS, NG] and

quarterly all members) to discuss emerging themes and potentially useful theoretical concepts with which to interrogate the data. We identified Rogers *et al.* (2011) model of systems of support, informed by a review from Vassilev *et al.* (2011), and that led to a second cycle of analysis, using the four systems model as a template. We refer throughout to types of ‘management’ that systems of support address rather than ‘work’, which focuses more on the impact on everyday activities of living with a NCD. Our use of the term ‘management’ focuses on the prevention of ill-health and maintaining general well-being. Our analysis also provided the opportunity to test the utility of Rogers *et al.*’s model in groups that are ‘at risk’ of developing NCD as well as those living with a condition; to describe the extent to which support networks were one-directional or reciprocal; and to identify and explore the role of religion, a less tangible source of support, but one that was clearly present in the data.

Results

Characteristics of participants

The characteristics of participants are presented in Table 1. The majority of participants (N=15) were of the *Jat* caste- who had ancestral origins either in the ownership or maintenance of agricultural land. Despite Sikhism’s rejection of caste it remains prominent among Sikh diasporas. All first generation and two second generation participants were living with NCDs. The remaining participants were carers.

Linking systems of support to types of self-management support

We have extended Rogers *et al.* (2011) model to sub-categorise self-management into management of disease, symptoms, lifestyle and embodied well-being (Figure 1) to depict the relationship between self-management and sources of support. We also describe relationships by defining the direction of support between actors:

1. Health professionals provide support for disease management
2. Alternative sources of care and traditional medicine provide support for symptom management (i.e. symptoms associated with NCD or ill-health)
3. Community and identity group membership influence lifestyle management
4. Emotional labour and spiritually-centred families provide support for embodied well-being

[Figure 1 near here].

Health professionals and disease management

Health professionals (HPs) via the National Health Service (NHS), particularly general practitioners (GPs), were reported as a source of readily available and reliable health information, who referred patients to secondary care and prescribed medication. Across all generations of our sample, members demonstrated limited knowledge of the different types of services provided by the NHS other than GPs, e.g. community health centres, health trainers. For first generation migrants the GP was an ‘expert’ and the patient was merely the recipient of expert advice (this one-way transfer of support in a social connection is termed a ‘directed tie’

Our doctor was very good, he would always prescribe me very good ... he would be straight to the point, he would give us our medicine and we would accept it and remain quiet, he would tell us what tablets to take, we would take them and we would feel better (SK19-Female_First_Generation_65_Retired).

First generation accounts presented little evidence of a patient-centred approach advocated by Stewart *et al.* for people living with NCDs (Stewart et al. 2001). For second and third generation participants the GP represented a ‘knowledgeable expert’ for consultation. Searching health information without medical guidance was compared with the expertise and trustworthiness of the GP:

if I had a condition and I was thinking that I wasn’t too sure about it, what is it? I would probably research it and then I would probably book an appointment with my doctor and say look I researched this, is it correct? (SK01-Female_Third_Generation_20_Student).

First generation migrants placed greater importance on health professionals being ‘from the community’ (South Asian or Sikh) for linguistic reasons and because of shared cultural understanding:

Some things you can’t communicate to White people, certain words don’t exist in English and it becomes much more difficult to explain, but with our own people who speak the same language, then they can understand, they understand our culture, the way we live, then it becomes easier for us (SK18-Male_First_Generation_42_Construction worker).

Conversely, greater cultural-religious distance for second/third generation participants was sometimes preferred, particularly when health seeking behaviour potentially crossed community taboos. This was particularly the case for women:

They shouldn't be like thinking, 'Ok if she's taking the contraceptive pill and she's Asian, what's she doing?' or 'she's doing this or ordered this'. That's why I don't like going to Asian doctors because some people they look at you like that and at this doctor's, the one that I'm at, he's completely different to my mum's, it's totally opposite, you just walk in and walk out (SK01-Female_Third_Generation_20_Student).

The greater confidence of second and third generation descendants to assert and expect a certain nature of care, may in part, be a reflection of their increasing social and economic status in wider society, their awareness of their own medical needs and the changing attitudes more widely in society to the role of 'doctor as expert'.

Alternative sources of care and traditional practices for symptom management

The system of alternative sources of care and traditional medicines included herbalists, traditional healers, remedies from the subcontinent, the internet, free-to-air television channels and radio stations. Alternative sources of care, such as traditional medicine, constituted directed ties (provider to patient) offering supplementary medication and health advice relating to the management of symptoms associated with NCD or ill health. A positive feature of the system is the ease of accessing health information from a range of sources:

the *desi* [Indian] remedies the doctors [traditional healers] on TV talk about, like cumin seeds being good for you, ginger being good for you, for our health, to prevent phlegm (SK17-Female_First_Generation_70_Retired).

it would be a look on Google, yeah so a Google search, it would be a search idea off my own back (SK02-Female_Third_Generation_24_Health Sector Manager).

Differences across generations became evident with poorly educated older migrants solely reliant on verbal information limiting the resources that could be potentially accessed with regard to self-management. For migrants, interactions they had with alternative sources of care were interpreted against the backdrop of trusting relationships with their GP:

I can only gain relief if I go to the doctors ... they tell you plenty about them on TV, that this [Indian] homeopath gives this medicine but I don't think I will be able to gain relief (SK13-Female_First Generation_70_Retired).

Remedies were used for more minor medical issues such as headaches or symptoms related to previously diagnosed conditions but not for what they perceived as a more medically serious condition.

The use of the internet was exclusively described by second/third generation participants. However, without face-to-face contact or an established method of searching, participants were critical of the credibility of online health information and still relied on their GP:

There are loads of symptoms flu could be for... so I'd rather get the expert to tell me than me telling myself. I might look on the internet just for knowledge but I won't get the right diagnosis because I'm not medically qualified (SK06-Female_Second_Generation_42_Banking Sector Manager).

Community and identity group membership influence lifestyle management.

Younger women referred to an expectation to conform to certain feminine values such as abstaining from eating meat and drinking alcohol, which the majority of first generation women adhered to:

Back in India women never ate meat, they would say that if you eat an animal then you are eating a person, that is when men ate meat and women couldn't, so they didn't want women to eat meat. Nowadays women eat more meat than men, they drink more alcohol than men, in past times which woman would drink? No woman would drink (SK17-Female_First_Generation_70_Retired).

For second and third generation women these cultural and religious values were in tension with their 'British' identity:

I don't think that drinking is seen as wrong, but to be honest within the second generation it's becoming the norm ... well we're in a liberal English country (SK06-Female_Second_Generation_42_Banking Sector Manager).

Practices were often fluid, and decisions about drinking alcohol or not had to be managed depending on the social situation. The practice of drinking alcohol and encouraging others to drink is well established among *Jat* Sikh men and adopted by the second generation as part of their own *Jat* Sikh identity that overlaps with White British cultural perceptions of masculinity:

there is almost a *Jat* culture where you have to have too much to eat and too much to drink and you have to force it down people's throats, but you don't see the same thing happening with some of the other castes (SK09-Male_Second_Generation_51_Private sector employee).

my Dad says everyone that works hard should drink, we're entitled to drink because we're *Jat*, we should all drink alcohol, its being a man (SK07-Male_Second_Generation_22_Social care employee)

In contrast to women, the interplay of caste and masculine identity for male participants allows men to engage in practices that are religiously prohibited.

The expectation to conform to established cultural values and practices along with being hospitable towards guests was understood in relation to *Seva*: the provision of selfless service. The preservation of *Seva* was bestowed on Sikh women, where offerings of food were a symbolic gesture of family social and economic status and value was placed on presentation rather than acceptance. Nonetheless, any attempt by guests to reject such offerings, even in the name of 'health', was done so with caution:

they think that you don't like their food, but I say "I hope you don't mind, I have these conditions and I can't eat these foods". Some understand, others still say, "you have to eat something" (SK10-Female_Second_Generation_45_Estates management employee).

Emotional and spiritual care in families and wellbeing

The 'family' referred to by Punjabi Sikh participants in this study, represents an extended family consisting of parents, grandparents, children and aunts/uncles living in one household or nearby. This system of support contains others that the participants trusted to empathize with them and maintain confidentiality, mitigating any fear of exposure of their personal issues to the wider community. None of the participants in the study mentioned discussing personal issues or causes of emotional distress with individuals outside of their families:

If you tell someone else your household problems, then they make one problem into two or three problems, they make up many things, the issue might be quite small but when they tell someone else they will make it something big (SK10-Female_First_Generation_65_Retired).

A key feature of the system was women seeking emotional support from other women in their family. Married women were expected to maintain ties with their family of birth and their in-laws, therefore expanding their kinship network, and accessing support outside of medical intervention:

you know how our [Sikh] women are like, they have many worries in their mind ...we think about ourselves, our children, our brothers and sisters, and when we hear of someone else's [emotional] pain that's it, we can't stop thinking (SK04-Female_First_Generation_56_Homemaker)

The affinity of a shared experience with members of immediate family led participants to believe that relatives were suitable individuals to access for emotional support. The family also provided physical care and practical help because children, usually daughters, played a

significant role in helping older relatives to self-manage their NCDs on a daily basis. This practice was bound up with a sense of familial (and gendered) duty felt by both the first and subsequent generations, which demonstrates the durability of this system of support over time:

It's the children's responsibility, it's my girls' responsibility, make phone calls, write down my prescriptions and collect them, to take me to appointments (SK20-Female_First_Generation_68_Retired).

However, for younger second and third generation women, the sense of obligation to fulfil this gendered duty of care may be challenging as they try to combine it with employment, personal relationships and other commitments.

However, younger unmarried women cited fewer family and community sources of support and tended to talk about coping mechanisms that could be used in isolation, such as seeking support through prayer:

I generally pray every night... and it makes you feel, yeah I'm gonna be ok (SK06-Female_Second_Generation_42_Banking Sector Manager).

Prayer or the demonstration of spiritual belief showed the significance of having faith as part of a system of ongoing support. Religious responses to adversity were an expression of religious humility and the recognition of the limited control participants had over aspects of their well-being. Yet, rather than simply an acceptance of God's will, for women, ritual prayers increased emotional resilience:

I recite and listen to prayers, and with that the pressure you have in your mind, you never become angry...but I say if you pray, your anger, it will go (SK17- Female_First_Generation_70_Retired).

Participants, particularly women, explained that distress led to poor management of their health conditions and so increased emotional resilience was an important tool to maintain well-being which led to better management of overall health. Emotional distress and its management was discussed much less by male participants. Men tended to use elliptical language, but prayer was still identified as a coping mechanism:

when you are at work your mind remains busy so your thoughts are elsewhere, and when I have these experiences [of emotional distress] I pray (SK14-Male_First_Generation_51_Foundry worker)

Discussion

Summary of findings

In this article we have explored in-depth the prevention and management of long-term conditions and the types and source of support for self-management accessed by Punjabi Sikh participants in the UK. Our study contributes to the social science literature on medical diversity by demonstrating the value of an intersectional approach to addressing health inequalities; discussing the importance of gender, ethnicity, religion, class/caste and social geography (Schulz & Mullings, 2006) when understanding the needs of migrant communities.

We built explicitly on the review by Vassilev *et al.* (2011) on self-management and social networks, and identified a number of ways in which our participants' narratives added complexity and nuance to this review's findings. In terms of the support provided for chronic conditions the analysis above demonstrates the dominance of relations with a GP for disease management or family based on trust for spiritual care as well as the importance of wider membership of different networks along religious and caste lines. In an era in which medical practices have become globally widespread, the connection of specific healing practices to places can no longer be taken for granted, and this creates new 'spatial networks of contact and influence' (Krause, Parkin, & Alex, 2014).

The relationship with GPs was strong and well-established though older generations preferred matching of ethnicity and language. While some used traditional medicine or the internet to support symptom management, these sources of information and treatment were not fully trusted. Whereas all participants said they trusted health professionals (albeit with potential favourable bias towards GPs), first generation migrants preferred to adopt a passive, compliant role in health care decisions, and second/third generation participants, particularly young women, adopted a more transactional attitude, i.e. the desire to be treated quickly without social censor. This reflects other generational differences observed in the literature, such as the transition of diets after migration (Anderson *et al.* 2005) but also the importance of understanding the complex intersection of dimensions of inequality, rather than taking a simplistic approach to 'culture' (Viruell-Fuentes *et al.* 2012). Lifestyle behaviour interventions were not discussed, nor use of the number of free initiatives in the area to help people lose weight, drink less alcohol or stop smoking. Treatment and advice was mainly rooted in GP consultations, and no statutory or voluntary initiatives centering on prevention were mentioned.

Many have made assumptions about South Asian communities, looking after their own (Afridi, 2011). The level of bonding capital (Putnam, 2000) (i.e. close connections between people with common backgrounds) is high amongst married women in the Sikh community acting as emotional support. The differential nature of kinship networks in the context of support was important. Unlike previous studies that focused on the majority White population (Rosland et al., 2010), the strongest affective ties in this study were not between partners but between married women within kinship networks. Although participants were not directly questioned regarding spousal support, there was no spontaneous mention of emotional support between spouses nor emotional support available for single men and single women in the Sikh community, but support by children/grandchildren for elders. Our findings differ from Singh *et al.* (2012), who reported spousal support amongst South Asian migrant interviewees, in relation to emotional and practical support for diabetes management. Yet, there were similarities regarding the importance of not disclosing aspects of emotional distress beyond the family system because of perceived social stigma. In addition, within our sample, physical care and practical support was provided within the family, and was highly gendered being provided by women.

Common amongst many South Asian populations is the obligatory pattern of food intake rooted in conventions of hospitality and these have been shown to be hard to change even with participants living with type 2 diabetes (Lawton et al., 2008). The social symbolism of the consumption of food and drink is often viewed as a 'barrier' to a healthy lifestyle. However, our examination of the attitudes to and consumption of food and alcohol illustrates the values attached to culturally embedded and religiously justified lifestyle practices which are symbolic to Sikh community identity, illustrating the limits of reductionist approaches to

culture. Marked differences could be seen dependent on age, gender and caste (Orford et al. 2004; Johnson (2006) and are framed within the context of migration and environment (Bush et al. 1998).

Practice and policy implications

Our findings highlight the limitations of the dominant approach to ethnic diversity that continues to attribute the perceived unhealthy lifestyles of particular minority ethnic groups to single factors, such as, ‘cultural values’ or ‘cultural difference’ (Phillimore, 2011). Instead, diversity in the context of self-management can be seen as socially produced, emerging from networks of interaction which transcend boundaries, both official and unofficial (Krause et al., 2014). We have shown that for the participants in this study, lifestyle and self-management practices are, in fact, embedded in a complex set of social relations that includes spiritually-centred families, health professionals, and membership of different communities. Throughout, we have challenged perceptions of culture as an unitary phenomenon but detailing within group differences using an intersectional approach. Greater collaboration and involvement of populations with high CVD risk profiles in the design of healthcare services, could support the adaptation of health services to be more responsive to the needs of diverse populations. Qualitative work of this nature helps support larger scale work that examines the global patterns of cardiovascular disease and preventative strategies (Yusuf, Reddy, Ounpuu, & Anand, 2001) by examining how structural risk factors play out on a localised scale.

Despite growing investment in ‘lay’ health workers, the participants did not mention non-medical professionals as a source of support. Potentially, non-medical professionals can provide more time, have greater contextual understanding of community health practices, and address patients in a culturally sensitive manner (Rhodes et al. 2010; Sidhu et al. 2015). For

example, greater contextual understanding of varying caste practices and beliefs would benefit members of this community. However, trust is still high in GPs, and they are preferred over ‘alternative’ sources of support and therefore it may be most appropriate to provide patients with information and advice about other services that can support self-management via primary care. Racism, as an explicit topic of discussion throughout interviews was absent. Yet, there was evidence of perceived discrimination based on gender that was culturally contextualised. For instance, migrant members preference for consultations with members of their community centred on “fear of being misunderstood due to ignorance of cultural and religious practices” (Cinnirella and Loewenthal, 1999: 521) rather than fear of? being subjected to racism, whereas younger women were concerned they may be stereotyped and stigmatised if treated by a member of their community. .

Strengths and limitations of the study

The ‘sharing stories’ style provided participants with the opportunity to contextualize their accounts of self-management. The analytic generalizability of the study is enhanced by our engagement with existing sociological theories around social networks and support in the context of self-management. However, there are some limitations to our study. Our sample is small and would have benefited from additional participants to draw out intra-group differences by gender and socioeconomic status. As our sample was generated via family members acting as gatekeepers; therefore there is potential bias that participants may not reflect all aspects of the Sikh community. Our sample is selective as a result of our strategy yet we have attempted to seek intergenerational differences within a single religious/caste group. Within the limitations of the study, we were not able to pay explicit attention to socioeconomic differences in the sample. The conversational style within interviews may have left

some issues unexplored, such as spousal support, which could have been addressed with direct questioning. We would argue that while some of our findings and the methodology used may be transferable to other contexts, our study shows the importance of investigating the particular configurations of ethnicity, faith, generation and caste and the organisation of health services,. Finally, our focus on the four systems of support may have been to the neglect of other areas of interest.

Conclusion

In this article, we describe the nature and sources of support sought by Punjabi Sikh participants based in Birmingham, UK, for the prevention and management of the chronic health conditions that disproportionately affect their community. We described four main sources of support – health professionals, alternative sources of information and care, communities and spiritually-centred families – and their role in providing or inhibiting support for the management of disease, symptoms, lifestyle and embodied wellbeing respectively. We argue that this more nuanced, intersectional account of self-management that demonstrates the interacting effects of ethnicity, gender, generation and environment has methodological importance for the planning and delivery of responsive and effective healthcare services, particularly in the context of long-term conditions.

Health services are being reorganised so that self-management and preventive health care practices are locating outside of traditional health care settings in community settings.

Providers and commissioners need to engage the diverse communities that they serve to plan and manage this transition. The type and location of support that is accessed is influenced by intersecting influences of ethnicity, gender, and generation. The design and delivery of health services for diverse populations needs to apply an intersectional approach when cultural

adapting services to reflect diversifying beliefs, norms and values in transnational communities. This research sits in opposition to research which situates diasporic South Asian communities as responsible for their own unequal health outcomes as a result of unhealthy behaviours associated with reductionist views of “cultural difference”.

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